

Fargo Session – Comments From Participants

How did you find out about the focus group?

- Family Voices email
- Southeast Human Service Center
- Cass County Health Coordinator

Major problem:

- No support group – I need to talk about feelings, not just medical stuff
- Family to family works well, but I have to seek it out
- Docs and nurses don't know what you're going through
- Doctor didn't help me besides medical help – I need more info

How do you access info about programs/services?

- Internet
- Books
- Called DD case mgr.
- Shriners hosp. is helpful
- Go out of state a lot – they give you so much info
- ND has nothing for social camps or resources, teachers don't have much info
- MN has way more services
- When the school has events there's not room for special needs
- Need to get kids integrated between "special needs" and "normal"
- Grafton State School is way ahead of Fargo
- My son is not potty trained and not changed enough because they're too busy
- My daughter is paired with a mobile student and the first week of school there was no para so I had to be there – legally they don't have to have a 1 on 1 para
- Living in a small town (Hillsboro) my daughter is integrated with kids, the smaller school system is more accommodating
- We need to know what our rights are (blue book – tells you everything but what you need to know)

What other ways would you like to access information about services for your children?

- see it right in the school system
- NICU – right from the beginning in the hospital
- whoever gave the diagnosis
- have to have its own entity or it will be influenced by school
- before kids start school, there's lots of info
- had to tell case workers about the waiver because I was denied two times
- had to ask a bunch of times (pediatrician) to get the diagnosis
- run a bunch of tests and get therapy, but no diagnosis
- gotten more positive results from alternative medicine and they don't pay for it
- takes a long time to get mail prescriptions
- behavior changed through alternative medicine (also horseback and music therapy) (works well but you pay for it out of your pocket)

What other ways would you like to access information about services for your children?

- try to keep problems away from your children
- want to work outside of the home at least part time, but don't have enough time
- get 6 hrs. or respite care so I have to quit work
- daycare around town – don't like to take kids with special needs
- people talk about doing it but don't follow through
- we don't have child care (did daycare out of my home for special needs)
- they discriminated against my daughter because of her special needs and daycare didn't take her – put in a complaint at Capitol and didn't hear back
- We want our kids with normal kids
- Meritcare has Halloween party for disabled kids and I thought it was terrible (got feeling of circus with the news media)
- Media maybe brings awareness of these kids
- I feel positive about services I've received, but I'm not in school system yet
- Made the doctor ways until he talks to me – we shouldn't have to push for help that much

Additional comments?

- Need to know what can we do together to make changes instead of getting them to help us
- Parents like us should be working at human services
- Keep having to rearrange our work schedules for our kids – I've been lucky to have an accommodating employer, but a lot aren't accommodating
- Why can't Meritcare come after hours? My insurance also won't pay for that anyway. Why can't PT's work a couple nights?
- They won't pay for us to travel the extra miles for services
- Need to get help obtaining specialized services out of state
 - o MA denied us to go to children's hospital in Gillette because there's a part time sleep disorder specialist in Bismarck – not going to help her
- Exhausting emotionally – need to pick and choose what I fight for
- I feel like an outsider – CLS and AARC services were horrible – my daughter is at Anne Carlson in Jamestown and she's doing great – I was worn out and couldn't do it any longer – now my daughter is role model there for other kids who can't do as much as her
- Every time if my daughter's gone out of state for over 30 days she loses her benefits – what can we do if there aren't services here?
- Why don't we have better child group home in Fargo (Anne Carlson is good but is in Jamestown)

Role of Children's Special Health Services (CSHS) Program?

- 4 people have heard of it
- What should they be doing?
 - o Have team of parents involved
 - o MA programs
 - o Providing grants for child care
 - o Money provided
 - o Communicate with state insurance companies in health insurance
 - o Why are these agencies for families NOT hiring families?
 - All of our time is volunteered and we have to work also – we're busy with money, work and taking care of kids
 - Any major profit company has consumer boards
 - Some meetings and groups need to take place on evenings and weekends with child care available

Other comments?

- self insurance through companies could be a valuable way to make medical payments other than regular insurance
- insurance will not pay for speech therapy because they say it's educational, not medical
- Medicaid won't pay for services if they're in schools, no matter how bad the services are
- Child needs speech therapy badly but it isn't covered – not getting enough at school
- Therapists need to be stationed in schools – they're floating right now
- My son needs to be changed at school to go to the bathroom, but he's 9 and doesn't want a woman – he needs to go every hour

What one thing would you want to change?

- have a network set up to help direct people to go for services, support and finance and play dates
 - o children need to interact with normal kids and with kids with special needs and get medical staff involved (therapists, nurses)
- permission slips to exchange information but it never happens
- made a booklet of how to care for my child – wanted it worded that way in IHP
- We need a pediatric surgeon in Fargo – we have to go to Minnesota
- We need higher income guidelines for people on Medicaid
- Our of all states, ND income guidelines are so high that they move out of state to get better care – why does a family have to suffer until the child is 18?
 - o We have no retirement or college fund because we're not allowed to
- Need AF/AC type thing where if you need this you get this much
- These kids are our future, why won't the state help us more?
- The financial burden on families is the biggest problem
- It costs the state \$127,000 to keep my daughter in Anne Carlson, but I had to fight for every penny to keep her at home